

# Impact of ill patients on the family



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The aim of this article is to critically analyse and discuss the current literature related to the family pressures of chronically ill clients at home. This topic is worth to discuss as an extensive body of research suggests that chronic illness affects not only the lives of those suffering from disease but also the family members who care for them (Goldberg & Rickler, 2011). Attending to the impacts of chronic illness on family members is important because the physical and emotional health of family caregivers has the potential to influence the health, well-fare and successful rehabilitation of persons with such chronic illness (Tamayo et al., 2010). Therefore, a crucial aim of this essay is to discuss the influence of chronic illness on caregivers. Another aim of this essay is to explain the role of care coordination to alleviate burden from family members looking after chronically ill clients in their homes. The role of all personnel involved in care coordination is will be explained and the importance of communication among them will be discussed. Moreover, the facilitators and barriers to care coordination will also be identified. Comprehensive literature research will be conducted and CINHAL, education research complete and academic research complete and Med line will be searched using the terms: family burden/pressure, community nursing, patients with chronic illness at home, care coordination, barriers/facilitators to coordination and interdisciplinary communication. Research has shown that providing care to a chronically ill family member can have negative effects on the care giver's psychological health and physical well-being over a period of time (Roth et al., 2009). Nguyen (2009) states that family members of patients who serve as caregivers are more prone to mood disturbances, physical exhaustion, stress, poor self-care, and

other health conditions such as hypertension, high cholesterol, and depressed immune system. Caregivers often also are required to relinquish their own needs to meet the needs of the family member, and this can increase caregiver burden further. Tamayo et al.(2010) assert that family caregivers often report deficits in education and skills related to the patients' care, a lack of assistance from healthcare professionals, an absence of social support, and increasing stress associated with the patient's advancing disease condition. Goldberg and Rickler (2011) assert that families influence a patient's psychological adjustment to the illness, adaptation of behaviours that promote or delay recovery and adherence to treatment. Hence, the family members managing patients with chronic illnesses at home require health care professionals to coordinate care and render support through education, resources and communication (Etters, Goodall & Harrison, 2008).

Walsh et al. (2010) state that care coordination encompasses numerous aspects of health service provision provided by a multidisciplinary team comprising of medical, nursing and community-based social service providers. It is important for clinicians to realise that caregivers and patients continue to face significant challenges long after they are discharged from hospital and they need continuous monitoring (Chlan, 2011). Maeng et al. (2010) state that a crucial role of the care coordination team is to assure that family carers are assisted to meet the challenges of care. Care coordinators help the carers to closely examine the effects of care-giving on their lives and help them identify strengths that promote adaptation to loss. Furthermore, care coordination engages patients and families in reflective dialogue about how illness has changed their circumstances and suggests

strategies to overcome the stress posed by care giving (Engelhardt et al., 2009).

Community health and home health nurses working with families in a care-giving situation have an opportunity to reduce caregiver stress. Nurses should assess the care giver's physical and mental health, functional abilities, employment status, resources available, and feelings about care giving regularly during primary care visits. Having developed rapport with caregivers, nurses periodically should discuss openly with them any experiences of depressive symptoms, such as feelings of sadness, insomnia, irritability, or decreased appetite. Nurses then can refer caregivers to appropriate resources, such as a social worker, case manager, or community services (Nguyen, 2009).

A general practitioner (GP) in primary health care services acts as a "gatekeeper" who refers the patients to other healthcare specialists and is responsible for much care coordination. General practitioners often have long-term relationships with chronically ill patients and their families, therefore, they can easily identify caregivers' stress and refer them to appropriate services (Tjerbo & Kjekshus, 2005). For instance, it is likely that caregiver burden may prevent some carers from recognising their own nutritional needs. GP or community nurses may easily assess the caregivers' nutritional needs and refer them to dietician who may educate the caregivers about the importance of having a balanced diet to meet the challenges of caring (Silver & Wellman, 2002).

As an important member of multidisciplinary team, the care coordinator may support carers and patients by guiding them along the treatment pathway, ensuring access to appropriate information and support services as well as acting as a key contact. Care coordinator also ensures continuity of care by following-up with family carers and by ensuring communication between providers (Engelhardt et al., 2009). Imran et al.(2010) state that primary caregivers of patients with chronic mental illnesses have high rates of mental health difficulties, family burden and impaired quality of life. The responsibility of care-giving in turn can affect the primary care-givers' own mental health and they are at high risk of having anxiety, depression and related disorders. Therefore, a psychologist can help the carers to cope with their issues of emotional distress and anxiety. District nurses are also in a position to assess the psychological impacts of caring on family carers and may refer them to mental health nurses to review their mental health.

Nguyen (2009) state that social workers may assist family caregivers by arranging services that can assist them with financial and legal issues, work stress, and providing information on respite services. In addition, counselling and support group services may help families and individual caregivers develop improved psychological, intellectual, and spiritual coping mechanisms.

Havens et al.(2010) state that timely communication escalates coordination among different health care providers as it keeps them updated about patient progress and eventually relieves carer's burden. Atherton et al. (2012) adds that lack of communication among different providers such as a physician, physiotherapist, social worker, occupational therapist, case

manager, community nurse, and counsellor who often are not aware of what the other is doing poses a challenge to families caring for their loved ones. Miller et al. (2010) assert that care coordination breakdowns are often caused by failures to synchronise team members' efforts through effective communications. The team members need to familiarise themselves with the situation they will work with, i. e., who their fellow team members are, what is the severity of the case they need to work on, and what equipment or resources are available to them. Multidisciplinary team members also need to discuss the patient's and family care giver's current situation and develop a care plan. During execution of the plan, the team members should monitor each other's activities, give suggestions and process feedback in relation to the team's progress against its agreed plan (Miller et al. . 2010). Indeed, all members of the multidisciplinary team need to combine their knowledge to provide optimal care to the clients through effective communication. Kane, Groth and Randall (2011) state that the form and types of communication in use and necessary to support effective care coordination are changing. Research has shown that multidisciplinary team members communicate to each other using a variety of formal and informal means. The formal mechanisms include regular team meetings, video conferences, and handover notes. Informal communication include telephone calls and frequent face-to-face discussions (Kane, Groth & Randall, 2011). Healthcare teams need fast and easy ways to access the most up-to-date patient information from the many places they work. They also need to be able to effectively communicate and collaborate with each other regarding patient care. Technology may facilitate this communication with mechanisms such as the telephone, email and video conference (Brown, et al., 2009). Atherton

et al. (2012) also assert that a virtual multidisciplinary environment in which team members communicate using telephone, e-mail, fax and written communication may enhance care coordination. Atherton et al. (2012) further state that emails could be effectively used for the coordination of healthcare appointments by professionals; particularly scheduling, rescheduling and cancelling appointments, and providing prompts/reminders for attendance at appointments. Unfortunately, the complexity of technology and difficulty using many different channels of technology-based communication also present challenges (Kane, Groth & Randall, 2011).

As discussed previously, care coordination is a crucial element of providing effective care to the care givers, however, there are certain facilitators and barriers to care coordination. Walsh et al. (2010) state that multidisciplinary team meetings are considered an integral component for providing coordinated and collaborative care. Effective communication among care providers during these meetings facilitates care coordination, however, these meetings are not implemented as consistently or successfully as recommended leading to lack of care coordination. There are several impediments to the effective execution of these meetings such as time constraints, lack of administrative support for these meetings and dominant personalities limiting open discussions. Coordination is enhanced through communication that focuses on problem-solving rather than blaming. In healthcare settings, participants often blame each other when errors occur; however, blaming undermines coordination by causing information to remain concealed rather than being shared (Dougherty & Larson 2010). In addition, mutual respect among participants also intensify coordination, however,

members of different occupational communities may reinforce their own status by cultivating disrespect for the work performed by others (Engelhardt et al., 2009). Doyle (2008) states that effective leadership and management system is a strong facilitator of care coordination. In addition, dedicated time and resources, good communication and information sharing among staff, and awareness of the benefits of working together may also enhance coordination (Dougherty & Larson 2010) .

Walsh et al. (2010) state that general practitioners can have a pivotal role in coordinating care of chronic patients at homes, however, the current general practitioner shortage within Australia is also raised as a barrier to effective care coordination that could adversely affect patients' care across their entire chronic illness journey elevating family pressures. Another crucial facilitator to care coordination is the appointment of care coordinators to assist caregivers and patients alleviating issues regarding access to various services, however, these positions are limited in supply and over-worked. Coordination is facilitated when health care professionals have shared knowledge regarding each other's work and they work together in the care delivery process. Nonetheless, participation from different disciplines often reside in different thought worlds because of differences in training, socialisation and expertise, creating obstacles to effective communication (Havens et al., 2010). In addition, increasingly diverse population in Australia requires health care providers to become well versed in cross-cultural communication and lack of this skill among practitioners is a barrier to effective care coordination (Havens et al., 2010). Limited access to health information technology especially in rural areas is also a barrier to care



coordination. Although there are considerable long-term benefits for care coordination within a community care setting, the cost related to it is also a barrier for effective care coordination (Dougherty & Larson 2010). Other barriers to effective care coordination may include increased work load, lack of trust and confidence in the abilities of other service providers, lack of appropriately trained staff, separate documentation, overlapping of roles, limited resources, and lack of information sharing. Focusing on the benefits associated with multidisciplinary team working and taking a multi-faceted approach to overcoming barriers will help facilitate improvements in care coordination (Doyle, 2008).

In conclusion, as the number of chronically ill patients increase in society, it is important that the allied health team understand the family care giver. The community health and home health nurses are in a perfect situation to reduce pressures on the family members of chronically ill patients at home. By assessing and understanding the problems, the care coordination team can provide interventions that will be proactive and prevent further stress in the life of the caregiver, client, and family. There are facilitators and barriers to effective care coordination. Certain elements such as shared knowledge, mutual respect, and high quality communication that is timely, frequent and problem-solving may facilitate care coordination. On the contrary, lack of time, lack of respect towards other professionals, blaming each other, lack of administrative support to the meetings, dominant personalities limiting discussion are some of the barriers to care coordination. Further research is needed to overcome these barriers and implement strategies to support caregivers.